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ABSTRACT

The main functions of comprehensive health care are promotion, prevention, therapy, and rehabilitation, with an overall goal of health education in its many forms. The consumer has roles and responsibilities in health care which mesh with life as a participating member of society. Consumer participation in the planning and delivery of health services can have economic advantages if people are encouraged to take on greater responsibility for their own health and well-being. Thus, self-care practices at the level of primary care are a social and economic resource. In establishing health care priorities and goals, each country must ascertain needs and assess the composition and volume of demands for health care. Nineteen of the member states of the World Health Organization European Region responded to a questionnaire on their arrangements and policies for consumer involvement in planning medical care delivery. Highlights of the replies are appended. (FG)

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CONSUMER PARTICIPATION AND RESPONSIBILITY IN THE PLANNING AND DELIVERY OF HEALTH CARE

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1. Introduction

The original concept and title of the study, which is the subject of this report, referred to "consumers' responsibility for and participation in planning for medical care delivery". On consideration, however, it was apparent that this was unduly restrictive in its emphasis on medical care. Any attempt to treat consumer responsibility and participation adequately calls for its consideration within the broader framework of health care, of which medical care is only a part.

The threefold purpose of the short study carried out in August and September 1977 was:

(1) to describe various forms of consumer participation and responsibility in the field of health care;

(2) to consider their significance for the planning and delivery of health care;

(3) to discuss some of the principal issues involved.

This brief report is intended to serve as a discussion document. While reviewing a number of relevant topics, it is by no means a comprehensive account either of the literature or the subject. The select bibliography at the end of the report contains works that perform both these tasks more fully.

The body of the report is based on material on a study of the literature and discussions with various persons at the World Health Organization offices in Copenhagen and Geneva as well as at the International Labour Office, the United Nations Division of Social Affairs, the Sandoz Institute, and members of the Nuffield Centre for Health Services Studies at the University of Leeds. Material from these sources has been supplemented by information supplied by WHO Member States in the European Region in response to a standardized survey schedule. This information is summarized in Annex II.

2. Health care

In this report the term "health care" generally accords with the following definitions:

> "Health care implies not only the care of the acutely and chronically ill but also rehabilitation, case-finding, health maintenance, prevention of disease and disability, and health education."
>
> Comprehensive health care: "The promotion of health, the prevention of illness at all levels, early diagnosis and treatment of disease, and rehabilitation of the patients. It implies health education at all these stages." (1)

Health care in these definitions is somewhat more comprehensive than "medical care" (see Annex I). Health care is not limited to - or even mainly concerned with - medical services, but embraces medical, social, environmental and educational components and, by implication, the services organized in these fields. The operation and effects of these services are cumulative and incremental not only over time, but also in the manner that activities in each field are mutually reinforcing. These effects may be positive or negative, of course, but we must assume that the aim is to maximize benefits.

The main functions (or processes) of health care listed in the definitions above are: promotion, prevention, therapy, and rehabilitation; and suffusing all of these are the aims and activities of health education in its many forms.

It is appropriate at this point to quote again from the WHO publication from which the definitions of health care were taken:

> "The term 'health education' has a number of meanings ... In its broadest interpretation health education concerns all those experiences of an individual, group or community that influence beliefs, attitudes and behaviour with respect to health, as well as the processes and efforts of producing change when this is necessary for optimal health. This all-inclusive concept of health education recognizes that many experiences, both positive and negative, have an impact on what an individual, group or community thinks, feels and does about health; and it does not restrict health education to those situations in which health activities are planned or formal. In the more limited meaning health education usually means the planned or formal efforts to stimulate and provide experience at times, in ways and through situations leading to the development of the health knowledge, attitudes and behaviour that are most conducive to the attainment of individual, group or community health." (2)

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Additionally,

> "The focus of health education is on people and on action. In general, its aims are to persuade people to adopt and sustain healthful life practices, to use judiciously and wisely the health services available to them, and to take their own decisions, both individually and collectively, to improve their health status and environment." (3)

It follows from what has been said so far about the components and functions of health care and of health education that the maintenance or restoration of health are not usually matters that can be settled simply between doctor and patient. There are causal links between health and other circumstances or factors. These include employment, income level, nutrition, conditions at the workplace, environmental hazards and pollution, the quality of housing, education and recreation. Also involved is the individual's participation and status in a range of community (social and political) and economic activities.

An individual's "health" is not only something personal to him, it also has a social dimension. Besides its physical aspects, it is part of the intricate fabric of his life and relationships with others. Similarly, what are commonly known as the "health services" are part of a wider system of social, economic, and political services and institutions with which the health services are interdependent and interact.

Seen in this way, it is logical to aknowledge that the consumer has roles and responsibilities in relation to health care which are inseparable from those he has in connexion with the other intermeshing areas of his life as a participating member of society.

3. Health care and the consumer

Background

The development of modern western medicine coincides with the growth of complex, industrialized, urbanized societies which have generated - and become dependent upon - high levels of technology. Indeed, progress in medical science and technology has been part of the advances made over much wider fields and interacts with them in innumerable ways.

In developed industrial societies a combination of environmental improvement, better material and social conditions and scientific medicine have subdued and possibly eliminated the most common causes of premature death - most strikingly in the case of epidemic diseases. Associated with these changes, the major emphasis in the health services has shifted to attempting to deal with acute or chronic morbidity. Although considerable progress has been achieved in some areas of psychological medicine and in the application of psychological knowledge and understanding to other fields of medical care, technological medicine, with the hospital as its centre, has come to dominate health services.

Many observers (4-6) have commented on this trend and its implications for the patient as a person, for relations between doctor and patient, priorities in health care, the scale and cost of resources - and for its effects on other social policies. Fuchs, for example, has referred to the "technologic imperative" (7) in medicine, while Illsley (8) has written about the "engineering component", and quotes McKeown who sumarizes the approach thus:

> " ... Medical education begins with the study of the structure and function of the body, continues with an examination of the disease processes, and ends with clinical instruction on selected sick people; medical service is dominated by the image of the acute hospital where the technological resources are concentrated; and medical science reflects the mechanistic concept, for example in the attention given to the chemical basis of inheritance and the immunological response to transplanted organs. These researches are strictly in accord with the physical model, the first being thought to lead ultimately to control of gene structure and the second to replacement of diseased organs by normal ones." (9)

Marc Lalonde, Canadian Minister of National Health and Welfare made a related point when he commented:

> "In most minds the health field and the personal medical care system are synonymous. This has been due in large part to the powerful image projected by medicine in its role in the control of infective and parasitic diseases, the advances in surgery, the lowered infant mortality rate and the development of new drugs. The image is reinforced by drug advertising, by television series with the physician as hero, and by the faith bordering on awe with which many ... relate to their physicians." (10)

While scientific and technological medicine has made astonishing progress in the space of one or two generations, with incalculable benefit to millions, there have always been many who have remained sceptical, untrusting or hostile, and have avoided contact with established medicine. They have chosen to treat themselves, where possible, or to seek aid and comfort from a variety of practitioners outside the ranks of the established system - ranging from "quacks" and cranks to highly competent and responsible persons. The challenge to conventional western medicine in recent years has been international and takes many forms including natural health movements, women's health movements, folk medicine, acupuncture, yoga, meditation, and more widespread recourse to osteopaths, chiropractors and other practitioners of nonmedical healing.

Moreover, evidence from studies (11-14) suggests that the majority of people who feel some (usually non-acute) degree of illness either medicate themselves or wait for the symptoms to pass, only presenting themselves for professional consultation when the trouble persists or becomes more acute. Even then, they may go to an osteopath or chiropractor rather than a conventional licensed doctor.

Thus, while medicine has made enormous advances in developed countries, especially in the application of science and technology, large numbers of people either avoid or reject it. In addition, there is evidence that the numbers of active and articulate critics of health services have grown considerably in the past decade or so. Organizations of different kinds have proliferated among the groups referred to: those seeking alternative forms of medicine as well as those whose efforts, broadly, are directed more towards effecting changes within the framework of established medicine. Their criticisms and pressures for improvement or reform have focused on various issues or concerns including: the allocation of medical resources - where the more dramatic high technology areas (heart surgery, transplants) have received excessive preference at the expense or neglect of others (geriatrics, psychiatry, more routine care). Related to these are the needs of groups like the elderly, physically or mentally handicapped, children with specific diseases or disablements, and women. Low priority is also said to be accorded to preventive medicine and to health education. Comparatively little attention is paid to doctor-patient relations, particularly in hospital, to procedures for complaints and redress, or access to information. The accountability of medical services to both patient and public and public supervision and control over the nature and quality of health care are also questions that have been raised. Linked with this there is increasing pressure for more direct participation by the public - as "consumers" (in the broad sense) and as the ultimate providers of costly resources - in the running of services.

Not all of these pressures and demands are new. Some of them were being exerted in several countries as long ago as the first half of the nineteenth century - or earlier - and led to legislation and improvements in the fields of sanitation, public health, housing, industrial and social welfare, and education. Pressure groups, promotional and administrative organizations were formed in each of these fields often becoming official or semi-public agencies at a later stage.

It should also be noted that legal provisions relating to the medical profession and its unrivalled powers in respect of recruitment, education, training, granting recognition, and the ethics and standards of practice were the outcome of public pressure for more rigorous control over the nature and quality of medical care. There has been a resurgence of demands for change relating to health services in recent years, but they are more widespread and differentiated and, in some instances, have more ambitious goals than ever before.

Just as the pressures come from different directions and have various, though often related or overlapping goals, so they are generated by a variety of factors. Some of these factors are specific and easily identifiable. Thus, the death of a patient through neglect or mistreatment, the deformation of children owing to inadequately tested drugs, or deficiencies of care in a particular institution spark off a public outcry and campaign for changes. Other factors are associated with more widespread economic, social, and political trends in a country. Of these, rising material and educational standards seem to be the most significant, for they find expression in rising political as well as economic expectations and demands on the part of the private market and public sector. The contribution of mass literacy and the media of mass communication are of major importance in stimulating such demands.

Consumers have become better organized, more articulate, informed and assertive. The tide of "consumerism" has flowed strongly in many countries and across oceans and international boundaries. Currents have also spread from one sector of consumption into another. Initially, the most vigorous consumer activities were concerned with the quality of goods, and to a lesser extent services, in the private consumption market. But the experience and competence thus gained soon carried over into the area of public and social services (including health) adding impetus and scope to activities there.

Inevitably, efforts to improve the quality of goods and services also involve questions of moral and legal responsibility as between provider and individual consumer or the public at large. Suppliers are under pressure to be more explicit as to the qualities and limitations of the product or service offered.

In some countries, considerable progress has been made as manufacturers, distributors, public services and governments have yielded to persuasion or litigation. New laws have been passed, existing ones reinforced and official consumer advice or protection departments set up. Complaints procedures have been introduced or strengthened within health, welfare and social security services, and officials such as the ombudsmen or special health service commissioners appointed. In addition, steps have been taken in a number of countries to widen the participation of consumers in the planning or administration of health services (see Annex II).

The "consumer" defined

For the purposes of this paper, the term "consumer" has a variety of meanings, some of them distinct, others shading into each other. These different meanings and nuances also indicate the varying forms or degrees of relationship between an individual or group and the health services. Such relationships range from the patient, as the immediate and direct "consumer" of services, to the community as general consumers or beneficiaries, as in the broad area of public health. The majority of people will not, however, be making specific demands on grounds of illness at any one time. The relationship of the community as a whole to the medical services is indirect and tenuous for most of the time and latent rather than active.

In between the two extremes referred to the consumer is represented in or by an expending range of organizations such as patients' associations. There are groups of individuals with the same clinical condition (alcoholism; cardiac, renal or rheumatic conditions; multiple sclerosis; physical disablement; drug abuse or other addictions; mental handicaps and so on); groups campaigning on behalf of others affected by a particular disease or form of disablement, bodies concerned with the promotion of health education, and many others. Most of these organizations are voluntary in origin and membership, but it is common for them to receive financial support from public sources (local and central government) and, there is a tendency for them to employ trained administrators and other qualified staff as they become better established.

Groups of consumers who have an interest in health and are actively engaged in promoting or protecting it are not necessarily concerned primarily with health. For example, trade unions, youth groups, associations of housewives or pensioners and schools may all be concerned over health care or health education in different ways.

Examples of different kinds and degrees of consumer involvement in the planning and delivery of health services are given in Annex II.

Of significance in many countries is the appointment or election of consumer representatives to committees or other formal bodies concerned with the administration of health services. The functions of such representatives vary, as do their power and influence over policies and administrative decisions. Some are restricted to consultation and observation over a confined area of topics, others participate fully in the sense that they share responsibility in the planning, direction, and administration of services.

Consumers' multiple roles

Just as there are many kinds of consumer involvement with different facets and aspects of health care, so the individual consumer engages in a number of roles, some of them at different times but others overlapping during a particular period.

The roles played by consumers in relation to the planning and delivery of health services may be categorized as follows. (It should be noted that these roles are interrelated and their effects on health care or the form of services are cumulative.)

Role played by the consumer:

Object: e.g., viewed from the practitioner or supply side; a potential user and target of services;

Recipient: e.g., as a patient, an active consumer;

Participant: e.g., during consultation or treatment, in interaction with the practitioner; as a member of a pressure, interest, self-care, mutual care, or service group; as a lay member of the administration or in another representative capacity; as a citizen;

Informant: e.g., as patient; as member of patient's family; as member of pressure, interest, self-care, mutual care, or comparable group; in the following roles: recipient, participant, educator;

Educator: e.g., as patient, participant, informant;

Monitor: e.g., as patient; as member of patient's family; as member of pressure, interest, self-care, mutual care, or comparable group; as lay member of administration or in other representative capacity;

Evaluator: e.g., as under "monitor"; these two functions or processes are particularly closely related and each of the kinds of consumer mentioned contributes, formally or informally, systematically or otherwise, to both (as to the others).

Consumers can aid or influence the planning and delivery of services in a variety of ways. While some of these may be more effective or useful than others, it will not always be possible to single out any specific one for evaluation. For instance, the effectiveness or utility of a particular form of consumer representation or participation may depend functionally, in greater or lesser degree, on other forms of past or current consumer activity. Less directly, it may depend on the "climate" of knowledge or opinion (probably on both) which has developed over a period as a result of the words and actions of large numbers of individuals and groups. Thus the effects and benefits of consumer pressure and participation are both cumulative and interdependent.

4. Consumer participation - advantages and limitations

The pressures for greater consumer involvement in health care and the forms they have taken represent a substantial assumption of responsibility. The impetus springs from several sources, some of which have already been mentioned: the relatively strong emergence of "consumerism" as part of a popular demand for self-determination, sometimes associated with anti-authoritarian and anti-technology sentiments; changes in material standards and levels of education; and concern at neglect and maladministration in medical care.

In the main, these activities by consumers are manifestations of mature and responsible social behaviour and should be welcomed as such.

Other major advantages to be derived from greater participation and acceptance of responsibility by consumers lie in the related fields of economy, rationality and health education.

Economy

" ... sickness and health cannot be separated by a distinct boundary. There is a continuous gradation ...

... the public have a virtually unlimited scope for regarding themselves as being sick, at the same time as they and their doctors have become increasingly able through technological progress to discover an increasing range of physical or biological 'abnormalities' in a purely statistical sense. It has been said that 'a healthy person is nowadays one who has not been properly examined.'" (15)

The increasing costs of medical and health services result from a combination of factors, the most important of which are:

(1) the changing size and age structure of the population (notably the disproportionate growth in the numbers of elderly and aged);

(2) rising expectations among the public;

(3) rising pressure from medical personnel (and the administrators of services) for additional, more sophisticated resources;

(4) improvements in the coverage (extensiveness, comprehensiveness) of services and in their quality;

(5) the continuous and rapid increase in the use of technology;

(6) general inflation in costs, prices, wages and fees, as they apply to medical and health services.

Another factor is the effect of the development of health insurance schemes covering the majority (or whole) of the population. These may be through social security, private or occupational insurance, a national health service, or a combination of these. Concern has been expressed in a number of countries that the existence of such schemes tends to free the doctor from cost considerations, with the consequence that he may pursue medical results without regard to cost (16).

Any overall reduction in the cost of health provision is improbable in the foreseeable future without some major change in the scale of supply, consumption or cost of one or more of the principal factors. Efforts to contain total costs must, therefore, be directed at factors which are (a) substantial, and (b) amenable to alteration without the introduction of harsh or arbitrary measures.

Economics which appear logical and reasonable, and which can be shown to yield positive benefits to health as well, have a greater chance of being accepted and supported by the public. Attempts to impose major changes in the approach to health care will inevitably meet with resistance from the medical profession and incomprehension and uncertainty from the public. If they are to produce enduring results, the processes adopted must be organic in nature. In other words they must depend on mutual adjustment and assimilation, advancing by means of education and cooperation.

The most obvious area to concentrate such efforts is that of primary care. Reference has already been made (11-14) to studies indicating that possibly three-quarters of health care is carried out without professional medical intervention. In the United Kingdom, perhaps a quarter of patients making contact with general practitioners could treat themselves, while almost as many would benefit by supplementing professional medical treatment with self-care.

It is clear that people already assume a great deal of responsibility for the diagnosis and treatment of themselves and those closest to them, especially members of their immediate family. Moreover, once a person reports to a doctor or other health worker a process of participation is initiated, and the successful outcome in terms of improved health may depend heavily on the quality of the collaboration which ensues.

The individual, his family, and even the local community are resources of health care and expertise whose potentialities have scarcely been investigated. However, there is encouraging experience in connexion with diabetes, mental illness and hypertension, and evidence from limited experiments in conditions as diverse as intra-abdominal surgery, asthma, haemophilia and congestive heart disease (17).

The education of the public or patient to understand more about the nature of illness and health, be more responsible in health care, and make more sensible and effective use of the means of care and treament cannot be free of cost, whether provided by lay persons or professionals. But, as a WHO group points out, "there are crucial differences between investments in lay and professional resources" (18). For instance:

(1) the lay investment may be potentially more progressive in that there are inherent economies in the utilization of the consumer as self-provider of health care;

(2) skills possessed by consumers are immediately available for productive output; and tend to be

(3) self-adjusting and discriminately applied according to self-observed effectiveness;

(4) self-care skills and experience can accrue, become assimilated as coping skills, and be transmitted to others.

Over time, therefore, the development of self-care, whether or not in association with professional care, may lead to multiple benefits, social and economic as well as in health.

The demand for health care is fed by a combination of needs and expectations. As such it is potentially insatiable in the context of modern industrial societies geared, so far, to economic expansion. The economic consequences of this demand in terms of consumption of costly and scarce resources is a matter of concern throughout the world. To help in reducing the rising demand for health care it is essential to educate both practitioners and public to a different perception of their responsibilities and roles. People should be encouraged to take on greater direct responsibility for their own health and wellbeing, and to accept that "health" is not a commodity or product that can be bought or supplied by doctors or health services. This calls for closer integration of the preventive, self-care, and curative approaches, with a greater emphasis on "healthy living".

This strategy, in turn, has implications for the balance between preventive and curative medicine. It will affect medical education and training, the nature of the practitioner-patient relationship, and relations between health services and the public. Essentially, it requires a greater degree of partnership (and, thus, participation) in contrast to the traditional paternalist model. No one form of consumer participation can provide the range of experience and inputs required to improve levels of knowledge, awareness, quality of service, and responsibility in a field as broad, differentiated and changing as health. It follows that different kinds and degrees of participation should be encouraged and facilitated.

Rationality

Rationality is used here in two related senses: in the first place a more rational use of resources, seeking to maximize the effectiveness and economy of their use. This is clearly highly desirable in such an expensive field as health care. It is likely to be attained if those responsible for making or influencing decisions make informed and objective judgements in relation to goals and priorities.

Secondly, rationality concerns "demystification". While recognizing that the trained practitioner will continue to play a crucial role in planning and providing health care it is important to dispel the "mystery" which often veils the practice of medicine from lay eyes.

If rationality is the foundation of scientific and curative medicine, it is also the essence of health education. It is impossible without it to encourage greater individual and mutual responsibility for health care. Knowledge is an essential element in fostering understanding and rationality.

Demystification would have beneficial consequences in different areas of medicine and health care, not least in contributing to the development of a more informed and effective interaction between doctor and patient in diagnosis, treatment, rehabilitation or after-care.

The process of demystification involves some transfer of hitherto professional functions (or elements of medical monopoly) to the patient or consumer, or at least sharing them with him. It therefore might be thought by some medical practitioners to question their status, power and capabilities, even reflecting on medicine itself. It also requires that the consumer accept a greater degree of responsibility for his actions and behaviour whether as patient or citizen.

Health education

Since health care embraces a broad range of a person's daily activities, living conditions, and work (see section 2, above) health education cannot be limited to a narrow focus. The priorities in health education should be directed to informing consumers about the factors making for health, and improving ability to care for and help themselves. More rational expectations of, and demands on, health services should be developed alongside a capacity to evaluate those services. The transmission of knowledge and skills between consumers should be promoted, so that health education is not solely something that is passed down from professionals or "the authorities". The assimilation and accumulation of knowledge and capability in relation to health and health care should in this way be reinforced.

The aim of health education, including consultations between consumers and professional personnel, should be to make people more aware and better informed regarding symptoms and diseases and how to deal with them. However, care must be taken not to stimulate excessive concern or over-anxiety. This could be counter-productive in its effect on health and actually increase the demand for medical care.

Although consumers may be able to take on the main responsibility for general health and to treat themselves with or without professional assistance in the great majority of illnesses, they are less likely to be able to do so in complex or acute conditions. Here they may be totally dependent on professional judgement and skills, at least in the critical stages. There will undoubtedly be times when diagnosis, assessment and treatment are beyond the unaided capabilities and resources of the individual or any lay help he can call upon.

The direct involvement of the consumer in determining or managing treatment is more feasible in relation to simpler, non-acute or chronic conditions. Even in such instances, however, as a patient or family member he has a number of participatory roles to play which contribute to treatment, convalescence and prevention.

The next section discusses consumer participation and responsibility in relation to primary care and self-care, the areas in which there is greatest potential for active consumer involvement.

5. Primary care and self-care

Despite the acknowledged pre-eminence of technological medicine and the hospital, primary care remains the foundation of the medical and health services. It is with the primary care services that the majority of consumers have their first, most frequent, and perhaps only contact.

Measures to improve the quality, availability and accessibility of primary care have generally yielded disappointing results, whether by redeployment of resources, organizational changes, or through professional education and training (13).

It seems certain that efforts to improve the quality of services will continue in all countries. However, two related questions are pertinent: first, is it wise, and in the longer term feasible, to concentrate efforts so heavily on the supply side of medical care, implying an ever-rising commitment of scarce and expensive resources? Secondly, will professional manpower resources ever be adequate in quantity and quality to meet observed, expressed, or foreseeable needs or demands for health care in the primary field alone?

It seems probable that the family practitioner will go on playing a leading role in primary health care, but that tighter limits will be set by economic and other constraints. Health care is labour-intensive, while the kinds of manpower required are expensive and must undergo careful selection and long technical, professional or administrative training.

In the circumstances and with the formidable constraints outlined greater attention should be devoted to exploring a massive reservoir of potential resources that has not yet been utilized in any organized or systematic way.

In order to complete the survey of resources available for health care and optimize their utilization it is essential to assess the nature and scale of the contribution that the lay consumer can make in the fields of self-care and mutual care.

It is now widely accepted that definitions of health involve cultural values and subjective factors, and that medical and lay perceptions of health are subject to change. Consequently, there can be no precise or permanent line of demarcation between medical and lay definitions of illness. Similarly, it is unrealistic to attempt to isolate primary care and self-care into separate, watertight compartments. Indeed, for the majority of people self-care is the form of primary care most frequently resorted to.

There is much evidence to show that "self-care practices are particularly prominent at the level of primary care both in terms of health practices and health judgements" (13). Consumers are, therefore, already very extensively engaged in the "planning" and delivery of medical or health care, but principally through individual decisions and expressed demands. Their influence by these means on the health services as a whole, and on health policy, is cumulative, largely indirect, and derives from the aggregate effects of individual decisions.

Functions and attributes of self-care

Among the functions which have been identified as part of self-care are:

(1) health maintenance,
(2) disease prevention,
(3) self-diagnosis, self-medication, self-treatment,
(4) patient participation in professional care.

This last contributes to the medical or health service staff's accountability to society through the following processes:

(a) the patient's use of the service and, in particular, why, when, and in what manner he expresses his demand;

(b) in the patient-doctor interaction - especially during prolonged treatment;

(c) by consumer involvement in political action, decision making, or at the more general but pervasive level of "public interest".

Lay or public interest and action in the area of health and of medical services draw upon a multiplicity of self-care capabilities (not only in health care), and involve the exercise of judgement by consumers regarding the competence of practitioners and administrators.

Levin et al. (13) classify the "operational objectives" of self-care in a way which indicates their different, but linked, dimensions:

(1) self-care as concerned with one's own health;
(2) the health of one's family or group;
(3) the health of one's community.

These sets of health care objectives are separable for analytical and operational purposes, but in reality, the health of individual, family, group and community are intermeshed and interacting. It is over-simple to view self-care solely in terms of individual self-interest. In the broader and more realistic sense self-care involves the individual in the performance of social and political functions. This implies the acceptance of certain responsibilities towards others (family, group, community) and also participation in a variety of activities with narrow or broad aims, but with the common objective of maintaining, restoring or improving health.

Self-care as a resource

The preceding discussion has essentially regarded self-care as a social and economic resource. The significance and potential of this resource are probably unquantifiable, particularly if its psychological and emotional dimensions are taken into account. It was also noted earlier (p. 8) that the potential contribution of self-care as a resource had not yet been systematically investigated. However, various studies in the United Kingdom (11-14) and elsewhere suggest that there is considerable scope for reducing the demand for medical servcices by encouraging a greater degree of personal (and family) responsibility for health care. It is, however, essential that this should be on the basis of better knowledge about disease and treatment. This implies either a larger allocation of resources to health education in its various forms or more careful attention to the goals, methods and techniques of health education, or both.

There is scope for consumers to make a greater contribution through accepting responsibility and active participation in the management, control, and treatment of chronic diseases, disablement, or handicaps with the object of lessening their degree or effects and reducing the demand for medical resources. These conditions, where long-term or permanent, all offer time for the patient, families, or other near groups, to develop and apply skills on a continuous and progressive basis.

The cooperation of the consumer, whether as patient or less directly as family, voluntary worker or part of the wider community, is important and even crucial in the prevention, treatment and aftercare of disease or disability. It can help with conditions of short-term or long-term duration, but is of utmost importance where they are chronic or acute. The role played by personal relationships and the morale of the patient in the processes of healing, recovery, and rehabilitation are well known.

What has been said about disease and disability may also be applied to the functional and other changes that accompany the onset of advanced years. Here again, the active involvement of the individual and support and cooperation of family and other groups are highly desirable.

As regards the patient, a disabled person, or an elderly person, certain goals or values should be emphasized, notably: independence; self-determination; maintenance (or improvement) of personal status and self-esteem; full access to the opportunities and entitlements of citizenship; maximum feasible participation in the technical and psychosocial processes of treatment; support, rehabilitation or other measures directed towards improvement and alleviation.

Functional concept of health

Greater prominence and emphasis should be given to defining health in functional terms, shifting the focus away from the negative consequences of disease or disability to the positive aspects of a person's capabilities. It would emphasize health, social and economic participation rather than disease and inability to compete with the fittest. Definitions of ill health would then be more closely related to those situations in which a person has to withdraw temporarily or permanently from society or to give up essential social or economic activities as a result of disease or injury. Where a person is able to function within limits imposed by his sickness or disability he would not necessarily be categorized as "sick".

Adoption of a functional definition of health would have implications for health education, professional education and training, and for the criteria to be employed in determining both the structure of health services and priorities in the allocation of health resources.

It would call for close cooperation between the consumer and the primary health care services but also encourage consumers - as individuals, families, or other groups engaged in self-care or mutual care - to exercise greater insight and responsibility with regard to their own health condition and that of others. Deriving from this, it is hoped that more realistic judgements and decisions would follow, influencing expectations and demands in respect of both health and health care.

Preventive care

The factors determining health are many and complex: genetic, environmental, physical and behavioural (including lifestyle). It is generally acknowledged that all consumers as citizens must accept responsibility for conducting themselves in ways which do not threaten or impair the wellbeing of others. In this broad sense, therefore, citizens participate in varying degree, and often without conscious awareness, in preventive care. They also participate extensively through personal judgement in immunization and vaccination programmes, mass radiography, and other forms of mass screening.

In recent years, consumers both as individuals and in organized groups have become increasingly active in combating environmental pollution. At the same time, partly as cause and partly as effect of these activities, they have become better informed about the contribution of environmental and behavioural factors to the generation or exacerbation of chronic diseases. To a greater extent than formerly, consumers have become more socially responsible in their own behaviour.

The association between over-nutrition, excessive drinking, smoking, insufficient exercise and stress on the one hand and on the other obesity, alcoholism, coronary heart disease and cancer, is increasingly widely acknowledged. Among the individuals directly affected and their families, growing numbers are engaged in preventive, supportive and curative activities. These highlight the often underestimated importance of psychosocial factors (and personal relationships), and the significance of personal and mutual responsibility in the prevention and treatment of disease.

6. Obstacles and hindrances

Obstacles and hindrances to the fuller development of consumer participation in the planning and delivery of heath care are of many kinds and differing significance. Their relative importance varies from one country to another and can also change with time. They include political and administrative traditions and institutional forms, involving differing perceptions of roles and responsibilities in these fields. Imbalance in the distribution of knowledge and skills between various groups in society also plays a part as do major differences in educational opportunities, standards, attainment and, especially, literacy. The values informing professional education, training and the ethics of practice affect attitudes, while the nature of social status relationships in general, and doctor-patient relationships in particular come into play whether determined by a hierarchical or egalitarian approach.

Other factors include the inadequacy and uneven distribution of social and economic resources, both generally and in the field of health care. Large-scale and complex societies also make greater consumer participation more difficult as do big distances separating people from each other, handicapping social contact and acquaintance with institutions concerned with health care. Whether people live in scattered settlements or close together in densely populated areas can be highly relevant. Communications including transport, especially in rural areas or between peripheries and centres in large urban areas, may be of critical significance in relation to opportunities for wider social participation or access to health care.

Some of the obstacles and hindrances referred to are the result of systematic actions by government and other official bodies even though they may be unintended. Examples of measures producing benefits in other respects, but generating difficulties for consumer involvement, include: legislation on the organization and functioning of health care services; the adoption of specific goals, functions and responsibilities for health service organizations which - if only by implication - determine the pattern of relationships betwen those inside the service and those outside.

Codes of professional ethics and rules of practice are also drawn up and applied systematically. They form part of the institutional apparatus defining and regulating relations between professional workers, their clients and the public. Professions are inherently and essentially exclusive in membership. This is clearly reflected in their ethical codes and rules of practice. These are not always benign in their purpose and can prove peculiarly resistant to change even when demonstrably inappropriate or obsolete.

While some of the hindrances to consumer participation are systematic in the sense employed above, others, such as cultural or traditional factors, have evolved more or less organically over a long period of time. They are part of the fabric of society and are bound up with people's attitudes, values, behaviour, social relationships and controls.

The scope for and pace of any extension of consumer participation and responsibility in health care are influenced by the composition of the amalgam of obstacles and hindrances faced in different places, countries, and at different times. Accordingly, the ease with which obstacles and hindrances can be removed or circumvented will differ according to the circumstances associated with place and time.

7. Conclusions - towards participation

Health care embraces medical, social, environmental and educational components and involves the services concerned with them.

The main functions of health care are promotion, prevention, therapy and rehabilitation. Health education is important in relation to all of these.

There are causal links between health and a wide range of social, economic, environmental, psychological, and behavioural factors. An individual's health is not only personal to him; it has social dimensions and affects other people.

Similarly, the "health services" are part of a wider system of interdependent and interacting social, economic, and political services and institutions which may be voluntary or official, formal or informal.

A consumer has roles and responsibilities in relation to health care which are inseparable from those in the other interacting areas and activities of his life.

Scientific and technological medicine based on the hospital has made remarkable advances and dominates the health services, yet the majority of people treat themselves when ill, and most patients require only primary treatment.

"Alternative medicine" has gained adherents in many countries. Sometimes associated with this trend, but largely independent of it, there has been a reaction against technology and paternalism, and consumers' organizations have developed strongly in health care as elsewhere.

Pressure from consumers for improvements in the scale, comprehensiveness and quality of health care has increased continuously with rising standards of material consumption. It is not possible to foresee any termination of the rising spiral of expectations and demand other than those imposed by economic constraints.

Associated with demands relating to the quality and quantity of services there has been growing pressure for more sensitive and responsive accountability to the needs and aspirations of consumers by the providers of services, whether politicians, administrators, medical practitioners or other personnel. This in turn, has been expressed as a demand for greater control over and involvement in the planning and delivery of services throughout their different stages.

In many countries, consumers have claimed that the established political, administrative or professional organizations and processes do not adequately meet their diverse and special needs and requirements. The emergence of "consumerism", with the proliferation of pressure and service organizations, is a contemporary feature of complex developed industrial societies. It is paralleled by the multiplication of pressure and interest groups in many fields other than health. These groups and organizations exemplify the "pluralism" which exists within the larger political, economic and social institutions that comprise the main structure of society.

In the health field, consumer representation has taken a number of forms: voluntary or statutory; ad hoc or institutionalized; independent, autonomous and operating outside the framework of health services, or participating as a formal part of health-service machinery; or in a variety of intermediate relationships.

The roles played by consumers are also diverse and span a very wide range of influence and participation. At one end of the spectrum is the influence of the patient during face-to-face relationship with the doctor. At the other extreme, consumers are engaged in "power sharing". They help to make policy, to take decisions about the goals, priorities, organization and the allocation of resources or the mode and pace of implementing decisions. They participate in considering the criteria and methods to be employed in evaluation, the extent and manner of accountability of the service and its personnel to patients and public, and other matters.

A review of different countries indicates that even where formal arrangements exist for consumer participation, the methods adopted and the scope of involvement vary considerably. In some cases, consumers are nominated by the authorities, in others they are elected. Usually, however, they are appointed by representative bodies like local councils, trade unions, or voluntary organizations rather than directly by the electorate of citizens. They perform various functions including, typically, acting as observers, guardians and advocates of consumer interests or, less often, sharing in the formulation of policy and running the services.

The effects and benefits of consumer participation in the planning and delivery of health care are dynamic, cumulative and tend to reinforce each other.

Through self-care, mutual aid, joining consumer organizations and in other ways summarized above, it is clear that consumers have already assumed a major share of responsibility for health care. But there are economic, social and health reasons why this involvement should be extended and made more effective.

Changes which appear logical, reasonable, and yield positive benefits to health are more likely to gain support from the public and the medical profession. Health education and cooperation between professionals and consumers are important means of facilitating such changes.

The most obvious area for concentrating efforts is that of primary care.

The individual, his family and the local community can provide health care resources and expertise whose potentialities have scarcely been explored.

In order to help reduce the rising demand for health care it is essential to educate both practitioners and public to a different perception of their roles and responsibilities in the maintenance and restoration of health.

Towards this end, the individual and the public should be encouraged to take on greater responsibility for their own health and wellbeing.

This calls for closer integration of the preventive, self-care and curative approaches, and an emphasis on "healthy living". It also requires a greater degree of partnership in health care between the professional worker and the consumer.

The attainment of rationality is an important goal both for medical science and health education. Rationality is the foundation of scientific and curative medicine. In the field of health education it encourages individual and mutual responsibility for health care.

There are limits to self-care - or other lay care - and thus to the degree of responsibility that consumers may assume for treating illness. Complex or acute conditions, for example, require the application of high levels of professional judgement and skill, but the participation of the patient (and those close to him) in diagnosis, treatment, convalescence, and aftercare are still important.

The direct involvement of the consumer in determining or managing treatment is more feasible in relation to simpler, non-acute, or chronic conditions.

In order to complete the survey of resources available for health care and to optimize the utilization of those resources, it is essential to assess the nature and scale of the contribution that could be made in the fields of self-care and mutual care by individuals, the family, and other kinds of consumer.

Definitions of health are affected by cultural and other subjective factors. Moreover, medical and lay perceptions of health change with time. Hence, there can be no precise or permanent demarcation between medical and lay definitions of illness. Nor can primary care and self-care be isolated from each other. For the majority of people self-care <u>is</u> primary care.

Greater prominence and emphasis should be given to defining health in functional terms, shifting the focus away from the negative consequences of disease or disability to the positive aspects of a person's capabilities.

This would call for close cooperation between the consumer and the primary health services, but also encourage consumers to exercise greater insight and responsibility with regard to their own health and that of others.

Cautionary note

Throughout this paper attention has been given to the extension of consumer participation and responsibility in health care and arguments for encouraging such an expansion. While recognizing the value and status of the individual it is also essential to see him in a social context. We should also give due weight to the social functions of organized and institutional arrangements which have developed over the years and make an incalculable contribution to the stability and welfare of communities.

There are dangers in an over-enthusiastic and uncritical approach to consumer involvement. Changes in methods, organizational arrangements and in the allocation of resources in health care should be preceded by rational enquiry as to aims and means, and a careful monitoring and evaluation of measures once introduced. The essential aim in health care is, where appropriate, to modify existing arrangements in ways that will make them more responsive and flexible to the health needs and expectations of the population, and more economical and effective.

It is argued that the greater involvement of consumers linked with health education and other measures, is the most practicable and rational approach to adopt in order to attain these goals.

8. The priorities

Planned developments in health care must take into account each country's health needs and expectations, social and cultural circumstances, political structure and traditions, the possession of or access to economic resources, and both shorter-term and long-term priorities within a comprehensive framework of social and economic policy.

In establishing priorities and goals when planning health care, the first task is to ascertain health needs and expectations and to assess the composition and volume of demands generated by them.

This requires systematic enquiry of adequate scale and coverage, followed by monitoring and evaluation either at regular intervals or on a rolling basis. The purpose of these enquiries will be to examine health circumstances and to determine the appropriateness and effectiveness of policy measures and of the component parts of health services including the administrative machinery.

A principal object of investigation, monitoring, and evaluation will be to identify the tasks in health care and how they may best be performed.

Since health care services are labour-intensive (and personnel account for 70% - 75% of the cost of these services), the critical questions of task performance relate not only to how they should be performed, but by whom.

In face of the pressures of rising demand and tightening constraints on resources in most countries, high priority must be given to manpower planning and utilization in health care. In addition to the contribution that increased participation by well-informed consumers can make in this area, it is necessary to examine:

(1) who can perform the various health care tasks adequately;

(2) what kinds of training (if any) they require;

(3) what kinds of health education (for professionals, lay workers, and the public) would effectively complement or could take the place of current training and practices.

The emphasis in education and training should be on producing suitably trained manpower rather than (as now) on producing a high proportion of highly trained personnel. Many practitioners in health care are over-trained in relation to the simple or routine tasks they are called upon to do. A more rational and economical approach would be to determine the minimum level of training required to equip personnel to perform satisfactorily (18). A corollary to this approach would be a careful analysis and allocation of tasks in health care and organizing the delivery of care to match the task assessment more closely than at present.

In this approach to the identification of tasks, to education and training for health care, and the utilization of manpower, industrialized countries may have much to learn from the experience of developing countries. WHO has supported studies in three countries (Brazil, Egypt and Hungary) which have yielded some useful comparative material on this topic (18, 19), but further experimentation and evaluation are required with a view to gathering and assessing experience in a variety of settings. There already exists a mass of information from other sources about different approaches to health care in non-industrialized and developing countries (20-22). The massive fund of accumulated knowledge and experience in self-care and primary care which the

countries of the world can offer merits very serious analysis. The most sophisticated and comprehensive international study (23) so far attempted was confined to selected countries in Europe and North and South America. Problems of data, methodology, and comparison are formidable, and the study just referred to has made a valuable contribution to knowledge and understanding of health factors and systems of care, but other areas of the world and patterns of health care merit equally rigorous examination and wide dissemination of the findings.

Primary care, linked with self-care and mutual care, is a key area both for study and for action to develop more extensive and effective consumer involvement.

The priority tasks within these fields are: identification of needs; evaluation of the effectiveness of care; providing an efficient feedback of information to services and decision makers about needs and the impact of measures; studying ways of instituting efficient, reliable, and economical ways of (a) evaluating self-care and self-medication, and (b) communicating the findings to the public and to health service personnel so as to effect desired changes in behaviour.

In order to attain these kinds of objectives, changes will be needed in the education and training of health service personnel and in health education generally.

It will also be necessary to develop ways of admitting consumers to the different levels and areas of organized health care dealing with the shaping of policy, the administration and delivery of services, and with monitoring, feedback, and evaluation.

It would be unrealistic to attempt to impose a universal blueprint for the kinds of machinery that would be employed to perform the tasks outlined above. Regard must be had to the demographic, cultural, institutional, political, resource, and other factors peculiar to different countries and other contexts.

There are, however, certain principles that can be generally applied while allowing for the flexibility and differentiation appropriate to different circumstances.

The formulation offered here is derived from the resolution on the "promotion of national health services relating to primary care" adopted by the twenty-eighth World Health Assembly in May 1975 (24). The objectives and principles listed are valid for countries at various stages of economic development, differing in size, resources, traditions, and systems of government.

General principles

General principles (24) for the development of primary health care and related activities and the optimal involvement of consumers are as follows.

(1) Health care should be "related closely to the life patterns and needs of the community it serves" and be designed to meet the particular needs of each community.

(2) Primary health care must be an integral part of the national system of health services (whether official, voluntary, mutual aid, or of mixed sponsorship and support). Other echelons or components of the health services should be so organized as to support the primary services.

(3) Primary health care activities should be fully integrated with the activities of other services concerned with the health and welfare of the community (e.g., housing, education, environmental services, recreation, social security, employment, social and economic planning).

(4) The local population should be actively involved in the formulation and implementation of health care measures and activities in order to match health care as closely as possible to local needs and priorities.

(5) The identification of local needs and priorities, decisions relating to health care, and the evaluation of activities should be derived from a continual dialogue between the people and the services. This requires the genuine participation of consumers in making and implementing policies.

(6) Health care should make the greatest possible use of resources within the community and in doing so should pay particular attention to: health education; prevention; the fostering of a rational approach and understanding; the need for economy in the use of resources.

(7) In line with these aims, primary health care should be designed and organized to integrate preventive, promotional, curative, and rehabilitative activities for the individual, family and community.

(8) The majority of health interventions should be undertaken at the most peripheral level of the health services consistent with the overriding aim of effective care. They should be performed by the personnel most suitably trained for the particular tasks. It is in these activities that consumers can participate most actively and fully in the delivery of health care. However, it should be re-emphasized that they have contributions to make throughout the entire field of health care and that they are entitled to be more closely and responsibly involved in activities which intimately affect their lives and wellbeing.

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ANNEX I

DEFINITIONS

The definitions employed are mostly taken from James Hogarth, Glossary of health care terminology (WHO, Copenhagen, 1975). A few have been modified by the author of this paper or formulated by him.

Allocation

The distribution of resources, tasks, responsibilities to and within a programme; a general term comprising such specialized terms as assignment, apportionment and allotment.

Consumer

No simple definition is possible. See pages 10-13 for a summary of the shades of meaning of the term, and the various roles involved. Essentially, however, a consumer is a person who consumes or utilizes goods or services.

Consumers, in the plural, may be functioning as such either in organized groups concerned with some particular form of consumption or utilization or be an aggregation of unorganized individuals.

Delivery

The rendering, or transmission of a service (including, for example, medical treatment or professional advice). In respect of health care, it is the ultimate stage in the implementation of policies.

Effectiveness

The degree to which a plan, a programme or a project has achieved its purpose within the limits set for reaching its objective.

Efficiency

The skill with which resources have been used to achieve a given end.

The essential difference between the two terms is that effectiveness is related to the results achieved (or planned to be achieved) and efficiency to the cost, in terms of resources, of achieving those results.

Evaluation

The systematic and scientific process of determining the extent to which an action or set of actions was successful in the achievement of predetermined objectives. It involves measurement of adequacy, effectiveness and efficiency of health services. It renders possible the reallocation of priorities and resources on the basis of changing health needs.

Health care

Health care implies not only the care of the acutely and chronically ill, but also rehabilitation, case-finding, health maintenance, prevention of disease and disability, and health education.

Comprehensive health care

The promotion of health, the prevention of illness at all levels, early diagnosis and treatment of disease, and rehabilitation of the patients. It implies health education at all these stages.

Health education

The term "health education" has a number of meanings, of which two are of special significance in the context of this report. In its broadest interpretation health education concerns all those experiences of an individual, group or community that influence beliefs, attitudes and behaviour with respect to health, as well as the processes and efforts of producing change when this is necessary for optimal health. This all-inclusive concept of health education recognizes that many experiences, both positive and negative, have an impact on what an individual, group or community thinks, feels and does about health. It does not restrict health education to those situations in

which health activities are planned or formal. In the more limited meaning health education usually implies planned or formal efforts to stimulate and provide experience at times, in ways and through situations leading to the development of health knowledge, attitudes and behaviour conducive to the attainment of individual, group or community health.

Or,

The focus of health education is on people and on action. In general, its aims are to persuade people to adopt and sustain healthful life practices, to use judiciously and wisely the health services available to them, and to take their own decisions, both individually and collectively, to improve their health status and environment.

Health services

Health services are difficult to define but can be described as a permanent countrywide system of established institutions, the multipurpose objective of which is to cope with the various health needs and demands of the population, and thereby provide health care for individuals and the community, including a broad spectrum of preventive and curative activities, and utilizing, to a large extent, multipurpose health workers.

A similar definition has been given for general health services.

Health service system

A health service system includes all formal and informal activities centred on the provision of health services for a given population and the utilization of such services by the population.

Medical care

Medical care is a programme of services that should make available to the individual, and thereby to the community, all the facilities of medical and allied sciences necessary to promote and maintain health of mind and body. This programme should take into account the physical, social and family environment, with a view to the prevention of disease, the restoration of health and the alleviation of disability.

Monitoring

Monitoring has the following functions: first, making routine observations and measurements of a process or activity; recording and transmitting these data; collating and interpreting the resulting data with a view to detecting changes consequent upon or associated with the process or activity under observation.

Planning

Planning is a process by which provision is made for resources required in future on the basis of available knowledge and through specialized methods and techniques.

Or,

Planning is an activity or series of activities aimed at the achievement of some future goal or goals (adapted from Manning, R.L., WHO, Geneva).

Primary care services

Primary care services are those offered by general health practice to the population at the point of entry into the health service system. Primary services are concerned with individual patient care as well as with community health. They are responsible for curative as well as preventive activities involving individuals and the community.

Primary health care

The advice and primary care given to a person or group of persons for preventive or therapeutic purposes by one or more members of the health or related professions, acting alone or as a team.

Or,

Basic curative care - simple diagnosis and treatment, referral of complex cases to a higher level - preventive care and essential educational measures.

Primary medical care

The medical care offered after a patient first presents with symptoms or signs of disease.

Secondary care

Secondary care comprises the care provided through specialized services on referral from primary care services.

Secondary medical care

Care requiring attention of a special nature, usually more sophisticated and complicated than could be handled by the general practitioner.

Tertiary care

Tertiary care includes highly specialized services and, where required, the super-specialties such as plastic surgery, neurosurgery and heart surgery.

Tertiary medical care

Care requiring highly specialized attention, and which can usually only be provided in centres specially designed for the purpose and by physicians trained as specialists.

INFORMATION FROM MEMBER STATES

1. The survey

As part of the review of consumer involvement in the planning and delivery of health care, the governments of Member States of the WHO European Region were invited in the autumn of 1977 to complete a questionnaire designed to yield information about the nature of arrangements in this field and about policies or views relating to them. The questionnaire is reproduced at the end of this annex (pp. 30-31).

Replies were received from 19 countries and the information given took the form of direct responses to the questions, expanded comments and explanations, and additional documentary material. The information from the various sources forms the substance of this annex.

The countries replying were: Algeria, Austria, Bulgaria, Czechoslovakia, Denmark, Finland, Greece, Hungary, Iceland, Ireland, Italy, Luxembourg, Norway, Poland, Portugal, Romania, Spain, United Kingdom, Yugoslavia.

A simple analysis of the totals of replies to particular questions is given at this point, but fuller analyses with extracted passages or complete statements follow in parts 2 and 3.

Simple analysis of replies (number of countries)

Question[a]	Yes	No	Other/not given
1. Are there formal arrangements for consumer involvement?	10	7	2
2. Are there informal arrangements?	10	8	1
3. Are these public or voluntary?	Public: 10	voluntary: 9	-
	Yes	No	Other/not given
4. Is consumer involvement encouraged?(1)	13	3	3
5. Are any regulations or legislation in force or contemplated?	11	6	2
6. Is consumer involvement successful?(2)	10	2	7
7. Are there specific organized consumer groups?(3)	12	6	1

Notes

(1) Although there may not be specific arrangements for consumer involvement in the health field, a number of countries commented that the views of a variety of organizations such as trade unions, professional bodies and consumers' organizations are invited and taken into account by the authorities when health questions and organization are under consideration.

(2) As one respondent commented: "There is no unequivocal answer to this question".

(3) This question was interpreted somewhat differently by respondents.

When interpreting the collated replies to the questionnaire it should be noted that not all questions elicited a full score of replies (notably question 6). Other questions were complementary (such as questions 1 and 2) where, for instance, a country might have both formal and informal arrangements for consumer involvement and these might be in either public or voluntary agencies or in both (question 3).

One of the hazard of posing questions that are direct and brief is that they tend to precipitate answers with similar characteristics. In consequence, the information sought might not

[a] For exact wording see questionnaire on pp. 30-31.

be obtained, as to provide it would involve fuller explanation and qualification than the question might appear to invite or permit. Thus, for example, the fact that a small minority of countries answered question 4 in the negative should not be taken to imply that consumer involvement in the planning and delivery of health care is actively discouraged. While there might not be specific organizational arrangements in the health field for such involvement, several countries commented that the views of a variety of bodies (e.g., trade unions, professional associations, general consumers' organizations, local authorities and different voluntary organizations) either were invited or, by law, had to be taken into account when policies were formulated or implemented.

The kinds of agencies which were consulted or which were part of the machinery of policy making and implementation, and the extent and influence of their involvement, differed from one country to another; involvement ranged from routine consultation to direct participation in decision making and shared responsibility for the determination of policies.

Some of the questions were differently interpreted in different countries. This is to be expected as a consequence of using a questionnaire which relies primarily on simple, standardized questions to collect information about potentially complex and heterogeneous arrangements in a substantial number of countries whose historical, economic and institutional circumstances and traditions are very diverse.

The replies to question 7 ("Are there specific, organized consumer groups?") reflected the differing interpretations placed on the question in the various contexts. In some countries, the "organized consumers" meant voluntary associations such as those concerned with diseases like rheumatism, tuberculosis, multiple sclerosis or blindness. In other countries, the term referred to representative bodies which might be part of or linked to machinery of health services, or, like trade unions, which, while they represented organized producers and consumers in a different sphere, were also considered to have an important contributory role to play in relation to health policies and services.

2. More detailed analysis of replies

2.1 Question 1: "Do you have formal arrangements for consumer involvement?"

Replies:

Yes	No	Other (including no specific information)
10 countries	7 countries	2 countries
Algeria, Bulgaria, Czechoslovakia, Hungary, Ireland, Poland, Romania, Spain United Kingdom, Yugoslavia	Austria, Denmark, Finland, Iceland, Italy, Norway, Portugal	Greece, Luxembourg

2.1.1 Countries reporting formal arrangements

Algeria

Relevant legislation and organizations include the code communal, code de la santé, social security agency.

Bulgaria

Both direct and indirect participation by consumers in decision making are taken into account.

" ... the most effective way in which the consumer can participate in planning and provision of health services is through extensive discussion of the organization and effectiveness of medical services with representatives of community organizations, managements or various organizations and associations and community services."

Czechoslovakia

"Included in such arrangements are semi-official public bodies and voluntary associations."

Hungary

"The Second Act of 1972 on Health in the following: Health Act/.

5.§.(1). In the fultilment of health tasks the society as a whole participates effectively.

88.§.(1). Social organizations participate actively in the protection of the health of the population, promote the proper use of facilities and installations serving health protection, and the realization of health goals. They offer effective help in the health education of the population.

88.§.(2). The health organs rely upon the aid of social organizations in the fulfilment of their duties.

88.§.(3). The organs fulfilling tasks belonging to the health sphere and the trade unions mutally support each other in their functons. Trade unions have the right to control the activities of organs fulfilling tasks belonging to the health sphere when these activities relate to workers. The legal rules pertaining to the health aspects of living and working conditions are issued by the Minister in agreement with the National Council of Trade Unions.

89.§.(1). The Hungarian Red Cross promotes by its activities the involvement of a wide section of the population in activities concerned with the protection of health."

The First Act of 1971 on the Councils stated in its preamble that the Councils ... effectively serve ... the interests of the population. The economic, cultural-educational, health and social political activities are realized through the Councils and with their effective participation.

It should be noted that social security is one of the tasks of the National Council of Trade Unions (SZOT). Cooperation between SZOT and the health organs is ensured by numerous committees at both national and council levels.

In order to make its work more effective, the council creates permanent or temporary committees. In general, there is a health and social committee attached to every council. The tasks allotted to the committees of the council are mostly ones which do not require council authority involvement, but which can be solved by drawing in social agencies.

The president and members of the committee are elected by the council. The president and the majority of the members must be members of the council, but in order to ensure expertise required for the solution of council tasks non-council members may also be appointed to the committees. In addition, the committee may draw non-members into its work in order to fulfil its duties. Thus, a network of activists functions with each of the 3-9 members of the committees. This, too, seeks to ensure that the work of the councils is directly controlled by the working people, and they have the right of speaking up directly in such matters.

Within the above framework, the committees:

(a) coordinate the work of the council, both the intra- and intersectoral activities; initiate the taking of measures; work out guiding principles and offer proposals to relevant council organs;

(b) participate in the elaboration and implementation of council plans and development programmes;

(c) offer opinions in more important matters to be dealt with by the council and executive committee;

(d) follow up and control the activities of administrative organs, council enterprises and institutions; study the possibilities of their development;

(e) exercise control over the activities of non-council organs in questions falling under council authority, particularly those of organs participating in providing for the population;

(f) organize the participation of the population in the implementation of council tasks.

Chapter 5.38 of the Council Act states that it is the duty of the member of the council to represent the interests of his/her electoral district and those of the population of the community, respectively; to keep up direct and regular contact with the population, to draw them into the solution of council tasks.

In Hungary, in addition to the officially organized council committees, the trade unions, as mass organizations of the working population, have the right and opportunity to participate voluntarily in planning at every level of health and social provision, by means of special health committees organized from their members, with the right to offer opinion and advice. Thus, for instance, there are industrial trade union health subcommittees at places of employment (factories, offices, enterprises, etc.) which participate in the planning and organization of medical and health care delivery at workplaces. At the regional level, there are county and metropolitan joint trade union health committees, which may offer opinions and submit proposals relating to the health and social work of the councils. At national level the Health Committee of the National Council of Trade Unions has the right to evaluate the planning, organizational and administrative activities of the Ministry of Health.

Finally, yet another mass organization, the Red Cross, has the formal opportunity to become involved - or to involve its members recruited from the population - in health and social activities, and this to a very wide extent.

Ireland

" ... a consumer protection role in a limited sense is performed by the National Health Council. This body was set up under statute to advise the Minister for Health either on its own initiative or in response to requests from the Minister.

The membership of the Council includes representatives of the medical, dental, nursing and other professions involved in the provision of health care as well as representatives of trade unions and women's organizations.

In addition, there are groups or organizations representing the disabled or disadvantaged sections of the community. Where such an organization is providing services similar or ancillary to those provided by a health board, its activities are usually supported by the health board. The types of organizations include those involved with epilepsy, the disabled, unmarried mothers and victims of family violence. Health Boards may give assistance, with the approval of the Minister, to such organizations. Recurring payments of funds for development are generally given on the understanding that the activities of a particular organization fit into the overall plans of the Health Board or of the Department of Health. Decisions on these matters are invariably made following discussion and consultation between the parties concerned."

Poland

"Directives of the Minister of Health and Social Welfare, 30 June 1973 (Official Gazette of the Ministry of Health and Social Welfare, No. 13., 1973) concerning the principles for the cooperation of units of the health services with autonomous bodies representing the inhabitants of towns and rural areas.

Ordinance of the Minister of Health and Social Welfare, 4 July 1975 (Official Gazette of the Ministry of Health and Social Welfare, No. 12, 1975) concerning the organization and objectives of services in the field of health care. The integrated health services, in cooperation with local government, community organizations, the unions and professional associations, are obliged to ensure that comprehensive health care and social care are available to people in their places of residence, work and education."

Romania

"The mechanisms regulating the participation of citizens relating to health measures, including the planning of certain health services, are:

(1) The General Assembly of Workers

Established by Law No. 11/1971 concerning the organization and administration of the socialist organs of the State.

The General Assembly of Workers is the supreme agency of collective administration, in which the entire personnel of the economic and social-cultural organizations participate directly, and in an organized manner, with a view to achieving closer integration; this includes the planning of activities and services in the health field.

At the same time, the Assembly controls the administrative bodies during the implementation of the programmes of action.

If the implementation of the proposals of the General Assembly is dependent upon the agreement of a higher authority, the proposals are submitted officially at that level. The appropriate authority is obliged by law to discuss, to take a decision and to inform the General Assembly of the outcome of the proposals.

(2) Sessions of the Popular Councils

(Communal, urban and district) established by Law No. 57/1968 relating to the organization and functioning of Popular Councils.

The sessions of the Popular Councils debate and initiate - within the framework of a national plan of economic and social development - specific measures relating to all that impinges upon the life of the inhabitants of their particular administrative district, including the protection of health.

It is laid down that in carrying out their activities the Popular Councils must engage in consultation with citizens about questions of general public interest. At all levels - communal, town, municipality, district - the Popular Councils constitute the optimal agency for the unrestricted participation of citizens both in the formulation and adoption of resolutions and decisions and in the development and application of the most effective ways and means of putting them into practice.

Contact with the general body of citizens through periodical meetings - within the framework of the sessions and with the Commission for Health - is kept constantly in mind with a view to obtaining the public's views on the implementation of measures.

(3) An important role in the participation of citizens in activities relating to the protection of health is also played by specific social organizations in our society (trade unions, the Women's Commission, Deputies, the Red Cross, etc.), which have the aim of representing and sustaining the interests of all citizens.

Through the direct participation of citizens, within the structure of these organizations, in the administration and the activity of community affairs, a growing number of workers play an active part in the establishment of the conditions necessary for community living and social cooperation, through measures and activities devoted to the promotion of health. As part of the unitary system of socialist democracy, these organizations work towards the fulfilment of both individual and general social interests, and through their multiple functions represent one of the effective means for constructive and responsible participation by citizens in the improvement of measures concerned with the protection of health.

(4) Bodies for the protection of employment, established in conformity with Law No. 5/1965 relating to the protection of employment.

The protection of employment and of the health of workers is also an important problem which involves all of those who work. Its fulfilment is one of the fundamental features of the organization of work, in all its parts and in all fields of activity.

The protection of employment is a constitutional principle comprising a body of obligatory norms, which have as their goal the creation of better conditions for the protection of life and health of workers, the prevention of accidents and of occupational diseases. In line with this, administrative agencies have, as an obligation, the establishment of protective measures appropriate to each place of work while ensuring that workers have a thorough knowledge of the regulations relating to security and hygiene at work which they must observe during their activities.

These responsibilities must be carried out simultaneously with measures directed to the fulfilment of production plans or the tasks of a particular service.

At the same time, the managements of agencies have an obligation to conduct periodical analyses, together with trade union and health organizations, of the causes of accidents at work and of occupational diseases, and to take the necessary measures to eliminate those factors which imperil the life and health of workers, as well as organizing medical treatment.

(5) One important method of participation by consumers in the planning and organization of the protection of health is by means of opinion surveys among various groups of the population (socio-professional categories, rural and urban populations, etc.). These investigations relate to problems of the organization and the protection of health, as well as the quality of medical treatment provided by the various kinds of health agency."

Spain

Through the governing bodies of hospitals, governing bodies of social security, and provinical representatives.

United Kingdom

"There are formal arrangements for consumer involvement through Community Health Councils (CHCs). These are independent statutory bodies, introduced on the reorganization of the health service in 1974, with a duty to represent the interests in the health service of the public in their districts. There is at least one CHC for each health district in England and Wales.

One-half of the members of CHCs are appointed by local authorities, one-third by voluntary organizations with an interest in the health service, and one-sixth by the regional health authority. Thus, five-sixths of the membership is appointed from outside the National Health Service.

CHCs are financed from National Health Service funds via regional health authorities and cost about £3 million in England in a full year. Their budgets are subject to approval by the Regional Health Authority (RHA), but in all other respects they are independent in their activities.

CHCs do not have a right to veto action by health service management, but they are entitled to be provided with relevant information (other than confidential material) by the area health authority to enable them to keep the local health service under review and to make such recommendations and representations as they see fit. They have a right of access to premises controlled by the Area Health Authority and are required to be consulted on any proposals for substantial developments of or variations in the local health service.

The present Government took certain steps to strengthen CHCs immediately on taking office. The most important were a new right of CHCs to observer status at Area Health Authority (AHA) meetings, and a special role in relation to closures of hospitals or health buildings, whereby a closure could be decided locally if agreed by the CHC and, if not agreed by the latter, would be decided by the Secretary of State provided the CHC had made a detailed and constructive counter-proposal.

More recently a national association of CHCs has been established by statute (from 15 August 1977) and over 70% of the councils in England and Wales have joined. The functions of the association are to advise and assist councils in the performance of their own functions and to represent at a national level the interests represented locally by individual councils.

A new circular asks Family Practitioner Committees to consider inviting CHCs in their area to send an observer to their meetings."

See also sections 2.2 and 3 below.

Yugoslavia

"Having in mind the necessity to clarify, to synthesize as much as possible the role and the place or the duty of the 'consumer' in planning and in planning participation, in the utilization of medical care, we note that in Yugoslavia the working people and the citizens as consumers of services of health organizations represent an integral part of medical care planning. Organized, on the basis of certain republic and provincial laws, into corresponding self-managing communities of interest, they make decisions, through their delegates, about all questions concerning their rights and duties in planning. They allot from their income or from the income of their organization the necessary resources, carry out social control, make plans for the development of medical care in the broadest sense, and are responsible for the situation in that field of social activity.

In assemblies of self-managing communities of interest, they decide, as the Council of Consumers, on equal terms with the Council of Providers of Services (the delegates or organizations of associated labour). Since the commune assembly allots from the income for those and for other common needs according to the plan of those communities, for ensuring solidarity and equality, assemblies of self-managing communities of interest are an integral part of the assembly system. For that reason, the Constitution and corresponding laws ensured to them equal status in decision making with the corresponding council of associated labour in the commune assembly or in the assemblies of republics and provinces. In that way the needs of various activities (education, culture, social care, health, etc.) are harmonized.

Self-management in all regions of social activities is based on the most direct participation in decision making by working people and citizens. By this means the State and its machinery, as intermediaries, are increasingly displaced. In the field of medical care only the working people and citizens, as consumers, and medical organizations and workers in those organizations, as providers of services, are responsible for the planning and utilization of medical care."

For a more extensive account of the variety of ways in which consumers participate in the planning and administration of health services in Yugoslavia, see The Public Health Service in Yugoslavia, published by the Federal Institute of Public Health, Belgrade, 1975. The principle of self-management is a primary one in the organization and administration of health services (pp. 40-46 and 65-71 of the above publication).

2.1.2 Countries reporting "no formal arrangements" (where replies were expanded)

Austria

Consumer involvement is indirect, i.e., through the press and other media regarding themselves as spokesmen for consumers; through public opinion surveys evaluating the degree of satisfaction with health services; and through contacts with elected representatives and voters.

Finland

See analysis of general comments below, part 3.

Iceland

See analysis of general comments below, part 3.

Norway

"There are no formal arrangements for consumer involvement in the planning for medical care delivery. However, informal arrangements, both voluntary and public, do take place and are encouraged by the heath authorities. There are indeed examples of successful consumer involvement. Consumer groups have been organized for handicapped people and for patients suffering from specific diseases."

2.1.3 Other replies

Greece

"There is no legislation or other machinery providing for the direct participation of the consumers of medical care in the planning of health services. However, the views of various groups of consumers (trade unions, professional bodies, etc.) are always taken seriously into account by those representatives of government responsible for health policy, when dealing with specific questions of health such as the setting up of a special agency for health, the future establishment of a hospital, etc."

Luxembourg

"It cannot be said that 'patients and their families' in the guise of 'special groups' participate in the planning of health services. In future, however, consumers will be able to take part in planning related to hospitals and also the allocation of medical equipment nationally through the influence of their paid representatives and the associations of health insurance schemes forming part of the National Council of Hospitals and of the Special Commission (Law of 17 December 1976)."

2.2 Question 2: "Are there informal arrangements for the involvement of consumers in the planning or delivery (including administration) of medical/health care?"

In most cases, the replies to this question were not expanded directly by respondents. Some, however, had already developed points relating to this question in answering question 1 or were to do so under "General comments" at the end of the questionnaire (see part 3 below).

The observations contained in fuller replies to question 2 were as follows:

Hungary

"Yes. In the form of opinion surveys, the health institutions, councils and trade unions analyse the satisfaction of the population with health care provision and delivery."

Norway

See also 2.1.2 above.

" ... informal arrangements, both voluntary and public, do take place and are encouraged by the health authorities."

United Kingdom

"Yes. Formal procedures exist for involving consumers in major decisions, but successful planning depends to a large extent on informal liaison between health service authorities and bodies directly representing the public such as local authorities, Community Health Councils, and voluntary organizations. Health authorities must also be sensitive to suggestions and complaints received direct from patients and take them into account in the management of services."

Yugoslavia

See 2.1.1 above and the publication (Belgrade, 1975) referred to.

2.3 Question 3: "Are these arrangements public or voluntary?"

Very few additional comments were made by respondents to this question. Again, it should be noted that information relevant to this question may also be given in reply to questions 1, 2 and 7 and under "General comments". The only generalizations that can be made with confidence are that in some countries the informal arrangements are due to voluntary initiative and organization, in others they result from and are supported by official initiatives and encouragement, while in still other countries, both voluntary and public agencies are involved, sometimes in collaboration.

Question 4: "Is consumer involvement encouraged?"

While consumer involvement is encouraged in the majority of countries responding to the survey, few of the respondents expanded on this. See parts 1 and 2.1 above.

Question 5: "Are any regulations or legislation in existence or contemplated?"

The field covered by this question was interpreted broadly to include consumer participation relating to public health, health education, inpatient or outpatient treatment, general practitioner or other in-community care or treatment, and consultative or administrative bodies in the medical or health fields. Legislation or regulations pertaining to consumer involvement were reported as being in existence in about half the responding countries and were either contemplated or in the process of introduction in a few others. Information, when given, is contained in preceding parts of this annex (1, 2.1, 2.2).

Question 6: "Where consumers are involved, is the scheme successful?"

Ten out of the 12 respondents giving a substantive reply thought so, but in most cases without developing or qualifying their replies. It would be prudent to bear in mind that one respondent pointed out "There is no unequivocal answer to this question."

Question 7: "Are there specific, organized consumer groups?"

In part, the reply to this question has been given elsewhere, in reply to questions 1 and 2 of the questionnaire. Two-thirds of the respondents reported that such groups existed in their respective countries, although not all gave examples. Taken together, however, the kinds of consumer organization mentioned covered a wide range of types of person, and by implication, functions. These organizations included such bodies as: children in kindergartens and children's homes; school groups; patients' associations; groups concerned with chronic diseases or conditions like blindness, cancer, coronary diseases, deafness, diabetes, epilepsy, mental or physical handicap or disability, mental health, multiple sclerosis; unmarrried mothers; victims of family violence; community groups; residents' committees; representatives of workers or special workers' committees, either within or outside the place of employment; health and social welfare committees; associations concerned with physical culture and sport; the Red Cross; and so on.

3. "General comments"

Respondents were invited to reply to the questions given below with a view to affording an opportunity for fuller definition or development of their answers. About one-third of the

respondents (6 out of 19) gave specific replies to these general questions. However, as stated above, due to the overlap between some of the fields touched upon or issues raised by thequestionnaire as a whole - itself an over-simple instrument to employ - the subject-matter of the two "General comments" questions had already been dealt with by some respondents.

The first of the "General comments" questions was:

"Do you consider consumer involvement as being direct or indirect (e.g., distinguishing between actually sharing in decision making and participation in consultative or advisory roles)?"

Replying to this question, four respondents identified consumer involvement as having an indirect relationship with policy making or decision making (Austria, Finland, Iceland, Norway); another pointed out that the distinction between direct and indirect roles was not clear-cut (United Kingdom) and the sixth respondent stated that consumer involvement was direct (Yugoslavia).

The replies from these six countries should be regarded as illustrative of the patterns of consumer involvement which have developed in a variety of national settings. It would be inappropriate to assume that the answers are proportionately representative of circumstances in Member States of the WHO European Region. The survey did not produce sufficient data to validate or invalidate such an assumption.

The replies were as follows:

Austria

" ... consumer involvement is ... indirect, i.e., through:

- press and other mass media ... as spokesmen of the consumers;

- studies of public opinion evaluating the degree of satisfaction with the health services;

- contacts with elected representatives and voters."

Studies show that "medical care delivery is being shaped considerably by the wishes and ideas of patients - an interaction which ..." is consistent with "the true function of the practising doctor".

Finland

"Indirect involvement in decision making by inhabitants of communes (primary municipalities) as the communes have the main responsibility for providing health services."

Iceland

"Indirect (consultative advisory roles)."

Norway

"Consumer involvement is indirect, as consumers participate in consultative bodies."

United Kingdom

"In health service legislation the functions of management and decision taking (by health authorities) and representatives of the consumer (by Community Health Councils) are distinct and separate.

In practice, however, the distinction is not so clear-cut. An observer from the Community Health Council attends meetings of the Area Health Authority and while he cannot vote he can voice the consumer viewpoint in discussion before the decision is actually made. In some health districts, CHC members participate as full members of health planning teams (who formulate proposals for local health service development for consideration by management). While, therefore, the consumer does not share formally in decision making, his voice is heard at the early stages in planning and this means that decisions will take the consumer viewpoint into account."

Yugoslavia

"We consider consumer involvement as being direct."

The second "General comments" question asked:

"If you favour greater consumer involvement in the planning and delivery of medical/health care, what do you consider as the most effective means of bringing it about?"

Austria

The "pattern and planning of the health services must ... be aligned with objective criteria (morbidity, invalidity, available staff, available equipment and funds). The most important task in the framework of the patient-involving formation of medical/health care is the suitable motivation of health personnel through training and education."

Finland

"Cooperation between public and private sections (consumers), especially in health education."

Iceland

"Through consultative and advisory roles."

Norway

"Greater consumer involvement might be brought about if the consumer organizations participated in decision-making bodies.

Increased consumer involvement in planning for health care is likely to be gradual and in many instances ... it will be a valuable contribution to the improvement of medical care delivery."

United Kingdom

"The Government is in favour of as much involvement as possible in the planning and delivery of medical/health care, and considers that the most effective way this can be furthered is through local initiatives by community health councils and voluntary organizations."

Yugoslavia

"Total consumer involvement and organized planning with the participation of the providers of services."

QUESTIONNAIRE

STUDY ON CONSUMERS' RESPONSIBILITY FOR,
AND PARTICIPATION IN,
PLANNING FOR MEDICAL CARE DELIVERY

1.	Do you have formal arrangements for consumer involvement?	Yes (if yes, please specify)	No
2.	Are there informal arrangements for the involvement of consumers in planning or delivery (including administration) of medical/health care?	Yes	No
3.	Are these arrangments public or voluntary?	Public	Voluntary
4.	Is consumer involvement encouraged?	Yes	No
5.	Are any regulations or legislation in existence or contemplated?[a]	Yes	No
6.	Where consumers are involved, is the scheme successful?	Yes	No
7.	Are there specific organized consumer groups?	Yes	No

[a] These terms are to be interpreted broadly to include, for example, public health, health education, inpatient or outpatient treatment, general practitioner or other in-community care or treatment, consultative or administrative bodies in the medical/health fields.

General comments

Do you consider consumer involvement as being direct or indirect (e.g., distinguishing between actually sharing in decision making and participation in consultative or advisory roles)?

If you favour greater consumer involvement in the planning and delivery of medical/health care, what do you consider as the most effective means of bringing it about?

It would be very useful if you could send us any relevant literature or documentation which you may have available.